The data available for ARTFL/LEFFTDS/4RTNI is listed in the "Available Data" and "ARTFL-LEFFTDS Data Dictionary." Additional data may be available upon request; for some forms, we provide summary variables only but may be able to provide more detailed responses.

Please note the following regarding the data:

A participant may be enrolled in ARTFL, LEFFTDS, 4RTNI, or a combination of projects:

- ARTFL: Advancing Research and Treatment for Frontotemporal Lobar Degeneration
  - Sporadics (Project 1): symptomatic with an FTLD-syndrome; no known family history or indication of genetic predisposition (Single visit)
  - Familial (Project 2): asymptomatic or symptomatic member of a family with either a strong family history of FTLD or a known FTLD-associated genetic mutation in the family. The participant does not have to know their own genetic status. (Two visits; ~1 year apart)
- LEFFTDS: Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects
  - Longitudinal – at least 3 visits anticipated, approximately 1 year apart.
  - Can be symptomatic or asymptomatic, but must be a member of a family with a known FTLD-associated genetic mutation. The mutation must be in one of the following:
    - *C9orf72* (expansion)
    - *MAPT*
    - *GRN*
  - The participant does not have to know their own genetic status.
  - All LEFFTDS participants are eligible for ARTFL and are co-enrolled.
- 4RTNI: 4-Repeat Tauopathy Neuroimaging Initiative
  - Healthy Controls or patients with tauopathy syndromes, including Progressive Supranuclear Palsy, Corticobasal Degeneration, and variant syndromes.
  - Additional visits at 6 months and 1 year.
  - Most participants in 4RTNI are enrolled in ARTFL as well.

Data are generally provided de-identified. This is an additional de-identification step from their study ID and removes all site information. If you have need for site information, or wish to combine the data with other sources using the GUID generated for each participant, please contact the ARTFL/LEFFTDS data management team.

Some notes on using the data: We provide several variables that may be used for classifying participants and guiding analyses. We provide suggested uses, but realize your analyses may require a different approach. Please describe your methods clearly in any resulting publications, which must adhere to the Data Use and Publication Policy.

Primary Clinical Phenotype:

- This is the clinician's diagnostic impression. We prefer this to the more categorical diagnosis provided through the NACC UDS D1 form. We also provide a confidence rating for the diagnosis.
- There are a few cases where the "Primary Clinical Phenotype" is listed as "Other, Specify". For these visits, the clinician did not feel that the participant met criteria for any of the listed clinical phenotypes. For these cases, the clinician is asked to provide a specific diagnosis. We leave it to your discretion for whether you include these cases in your analyses.
- Similarly, there are participants with psychiatric or "mild cognitive impairment" diagnoses. These may be valuable for classifying early disease stages, for example. If you require additional information for interpreting, you may request additional data such as the NACC B9 Clinician's Judgement of Symptoms.

Clinical Dementia Rating Scale (CDR):

We provide the individual domain scores for the CDR, including the supplemental domains for behavior and language. We provide the standard CDR-SB (6-item) and standard global CDR (based on classic CDR scoring rules). However, we recommend that you use the modified FTLD-CDR. For the sum of boxes, the 8-item FTLD-CDR-SB is constructed by adding all domain scores. For the FTLD-CDR Global, see the separate document "FLTD-CDR Scoring Rules".